

Patient Experiences of Terminal Illness Toward the End of Life: A Reflective Narrative Report

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The care of patients, towards their end of life, in the community is complex and challenging. We prefer to see them in their home environment, with their spouse or next of kin present, often accompanied by a junior colleague for help and support.

As I unfolded the piece of paper to confirm the address, I stared at the door in a foreboding gaze—I could clearly see and read 16. I must have looked at it for a long time since I still remember the geometric shape of the brass number and the contours of the wooden door. I took a deep breath and asked my colleague: “shall we . . . ?”

We knocked and waited for a long time. The doorbell was broken, so we knocked again. About 10 minutes later, a muffled shuffling sound was heard, slowly the sound got clearer and closer. The door sprang open and a soft low voice welcomed us: “Good morning, please do come in . . . I’m sorry, I was upstairs . . . I had you all in my diary . . . come in.”

He was frail and gaunt—bent forward with a pronounced kyphosis and still in his deep blue bathrobe at 1:00 in the afternoon. He appeared unkempt, so did his house but I thought: “at the worst, a house unkempt cannot be so distressing as a life unlived (1)” and it looked to me that O. J. Watson had lived a life. The house was full of stuff, sprawled all over the drawing room: books, newspapers, magazines, clothes, and framed pictures—you name it. The radio was on; BBC Radio 4, The World at One to be exact. He limped toward the kitchen and turned the radio off “that’s better,” then he motioned toward the couch and asked us to sit down.

Slightly breathless, he turned toward us and sat on the opposite couch and asked: “how could I help you, dear?” and without waiting to hear our answer he continued with a sardonic smile: “they [doctors] gave me 6 months [to live]; it’s been 10 years” the pitch of his voice changed as if to indicate a triumphant declaration.

O. J. Watson could be considered a hale octogenarian under the circumstances of his condition. In his eighties with a debilitating cancer, he is “carrying on” and has no intention

to “give up.” It all begun 10 years ago, in that fateful year he was diagnosed with malignant neoplasm of the prostate—but the story goes further back. “Many years ago, I complained to my doctor that I passed too much water and very frequently so, it was very bad during the night, I used to get up about 4 times—after a few tests, they reassured me that it was all fine—so I carried on, you see.”

He has a sound memory, perhaps he has been telling this story for many years. Like most patients with chronic terminal illness, O. J. Watson is a good storyteller. He went on to tell us at length how his back pain started and how it got worse, he was “passing blood” in his urine and had urgency and “serious problems” with his “water works.”

His pain killer tablets were somehow effective but gave him unbearable side effects. “Some of these drugs are dreadful”; he complained looking at his wife for approval or an acknowledgment that it really was bad. His wife nodded. Two days ago, he had been to hospital twice to sort out a blocked catheter and they had hardly slept that night or the previous night, in fact that entire week.

His wife hardly said anything. After an initial brief “good morning” she sat down and listened to us intently as if waiting for her turn. “I wouldn’t have coped without her in all these years.” O. J. Watson has a caring wife—I thought—and a daughter who lives down the road. “She’s teaching and has met a lovely Italian man recently” said his wife excitedly “we all love him, of course.” It sounded slightly off topic. But a conversation so heavy must be interspersed with something lighter.

He sounded hoarse but there was not an occasion that we struggled to make sense of what he said. He got up several

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times to bring his medication bag, his prescriptions, and his diary, in that order. He offered us tea. "I go to church, when I can," he said "my daughter comes here often and my grandchildren are lovely." As if he had anticipated, in fact pre-empted a question about what life meant to him. I had a sense that he was telling us that these are the things that take him through life: his faith and his family.

He never mentioned death. But it was there, all the time, like a giant elephant sitting in the corner; too present to be even mentioned. In Frost's words:

The present,
Is too much for the senses,
Too crowding, too confusing—
Too present to imagine (2).

It was, of course, hinted at ponderously but never eloquently. Perhaps because he has been anticipating it for far too long, 10 years of living with the fear, 10 years of premonition every morning and every night. It looked as if he had reconciled with the idea of mortality and it troubled him no longer. Not heroic but somehow resigned to the fact.

After years of palliative care, after a long period of coming to terms with his illness, he is still looking forward to meeting his oncologist and participating in trials "to see what he has got to say—if there is anything else." He reminds one of the complexity of responses to end-of-life issues. It is as if he is re-enacting a scene from *Anna Karenina*. After a long period of decline and struggle with consumption—at the end of his life—Nikolai Levin eventually comes to acceptance and faith but surprises Kitty (his sister-in law), as she is about to leave his room, by asking her: "Why don't you go and find the best doctor in Moscow (3)."

O. J. Watson vacillated between too much hope and optimism and a nonchalant resignation to fate. He was in the process testing the assumption among us, the health-care professionals, that a patient's emotional and psychological response to illness follows the pathological course of the disease. We think as the disease progresses so does the patient's ability to make sense, come to terms and make peace. We assume that over time it would be easier for patients to handle uncertainty and fear so when the time comes they would be ready to accept the death's cold embrace.

He will become increasingly more reliant on his wife, who herself is vulnerable, frail, and faltering away. Does he need a will? Not the sort of thing about his property and things, but something beyond things. Who will speak for his interest when he gets more unwell? What would he think if he learned that about 50% of all deaths in Britain occur in hospital (4)? Would his final days be drawn out to excruciating lengths in places he may not wish? I don't know, but I sensed that he would wish a quiet death as Sartre wrote: "that death would be taking only a dead man (5)."

"He is unpredictable" said his wife "just like the weather"—they both know he is no longer well but becoming

poor, occasionally very rough. But for how long would it be for a time?

As his doctor, I was preoccupied in a different way. What would be his immediate needs? How can I safely manage his symptoms? Do I need to discuss end-of-life resuscitation with him now? Are his paper works in place? How could I make sure that the nurses know about his most recent catheter infection? In short, I did not feel emotional; I could only connect with him in a cold and clinical way. I felt my heart was racing when I was going through the list of things that I had to do. Then, I stopped.

I thought of him as a father, a husband, a neighbor, and a human being. It all changed instantly: a strong outpouring of emotions that was very overwhelming, intense, and draining. How would I have dealt with him if he were my father? When I thought about it, pangs of despair overwhelmed me. It was an eviscerating reminder of the fragility of life and the inevitability of mortality. It was also a striking lesson on overcoming the barriers we often put between ourselves and our patients; by trying to keep that distance, we are in danger of feeling nothing toward the very people whose care we are entrusted. A reminder too that the dying may not always know how to die but they can teach us a lot on how to live.

It is sometimes easy to forget that those at the end of their lives are unique individuals with very complex needs and wishes. To appreciate their lives in full, to try and understand every word uttered, and to have an interest in them as humans. This is the art of medicine. It is difficult. I think very difficult. Training to understand how to manage their symptoms and control their pathological pain is crucial but is the easier part. When I met O. J. Watson as Henry David Thoreau once said I "fronted only the essential facts of life (6)." And for me those were mortality, meaning, pain, purpose, happiness, and suffering. Did I not know these before meeting him? I certainly did. Knowing is not the same as feeling. I needed a reminder—something to hold on to and never forget that we need to appreciate a life in all its fullness to become capable of caring for it.

Witnessing patients' narratives is an opportunity to connect with and get closer to their unique ways of seeing the world and their perceptive insights into the human condition. Their stories contain powerful emotions that give meaning to their experiences of illness (7). Patients are not just a collection of symptoms that could be dealt with clinical facts but rather individuals with "singular, irreplicable or incommensurable (7)" experiences. This is why narrative remains important and crucial in patient-centered medicine. Our ability to bear witness and make sense of their stories would make the practice of medicine more effective and satisfying (8).

Author's Note

The name of patient and his family—if given—has been changed. In addition, identifying details such as patient's age, profession,

familial relationships, places of residence, and medical histories have all been changed.

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